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ARTICLE

The role of spirituality in spinal cord injury (SCI) rehabilitation: exploring health professional perspectives

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Abstract

Study design Descriptive, qualitative study.

Objectives To explore the perspectives of health professionals (HPs) regarding the role of spirituality in spinal cord injury (SCI) rehabilitation.

Setting Single centre rehabilitation hospital, NSW, Australia.

Methods Two focus groups ($n = 12$) were conducted with HPs (e.g., nursing, allied health, medical) working in SCI inpatient rehabilitation. A semi-structured interview was employed, consisting of questions about spirituality and its role in SCI rehabilitation. The groups were audio recorded and transcribed. An inductive thematic analysis was conducted.

Results Six themes were identified from the focus group data: (i) the meaning of spirituality; (ii) spirituality as a help; (iii) spirituality as a hindrance; (iv) how spirituality is indirectly addressed in practice; (v) perceived barriers to incorporating spirituality into practice; (vi) how spirituality can be better integrated into practice. HPs recognised that spirituality played an important role in the adjustment of many individuals and their families after SCI. However, spirituality was not proactively addressed during SCI rehabilitation, and most often arose during informal interactions with clients. Spirituality, and specifically religious belief, was perceived to sometimes raise difficulties for clients and staff. The use of physical space and a review of rehabilitation processes were suggested by HPs as two ways spirituality could be better incorporated into practice.

Conclusions The findings of this study reveal that spiritual needs of clients and their family members during SCI rehabilitation are important and could be better addressed. A range of initiatives are proposed, including staff training and the use of standardised spiritual assessment tools.

Introduction

A spinal cord injury (SCI) is an unexpected and often life-changing event for an individual and their family members. Such an experience can raise spiritual or existential questions [1] which may contribute to posttraumatic growth [2], or even posttraumatic struggle or decline [3–5]. Spirituality has been closely associated with increased levels of quality of life, life satisfaction and resilience among individuals with SCI [6–11], as well as lower levels of depression [12–14]. Furthermore, spirituality has often been identified as a key factor in adjustment after SCI [5, 15, 16]. Despite these findings, no known studies have investigated the perceptions of health professionals (HPs) towards the role of spirituality within SCI rehabilitation.

Spiritual well-being has been defined as "a sense of harmonious interconnectedness between self, others/nature, and Ultimate Other … achieved through a dynamic and integrative growth process which leads to a realisation of the ultimate purpose and meaning of life" [17]. Although related to spirituality, religion has been defined as a distinct concept referring to "an institutionalised (i.e. systematic) pattern of values, beliefs, symbols, behaviours, and experiences that are oriented toward spiritual concerns, shared by a community, and transmitted over time in

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traditions" [18]. Whereas spirituality may encompass broader concepts such as meaning, purpose and hope, religion is generally understood to be related to the "formal system of beliefs held by groups of people who share certain perspectives on the nature of the world" [19]. As Swinton [20] has pointed out, there are many different approaches to spirituality, or different 'lenses' through which the meaning of spirituality has been viewed. The religious perspective of spirituality places emphasis on meaning and purpose obtained from an individual's belief in God (or a higher power), and the associated membership of belonging to a community of other believers. However, as demonstrated by Jones, Dorsett, Simpson and Briggs [21] and others [22] religious belief is one of several sources of spirituality. Spirituality can also encompass the process of finding meaning and purpose through the natural world, connectedness with others, and strength found within oneself. It is this broader understanding of spirituality which was adopted for this study.

Given the beneficial role that spirituality may play in adjustment after SCI, we were interested to consider how its role was perceived by HPs. A number of studies have considered the perspectives of HPs in other fields of health. Many of these have focused upon a particular discipline, such as nursing [23, 24], social work [25], medicine [26] and physiotherapy [27], with only a few considering the views of a range of HPs [28]. Findings from the above studies suggest that although staff consider spirituality to be an important component of health, barriers to addressing spirituality in practice exist.

This study aimed to explore the perspectives of HPs working in SCI rehabilitation towards spirituality. A range of perspectives within a multidisciplinary team were sought. Of particular interest was how HPs considered spirituality to be currently addressed in SCI rehabilitation, and ways practice could be enhanced.

Methods

Participants

Participants were members of the multidisciplinary team at the Spinal Injury Unit (SIU), Royal Rehab, a spinal inpatient rehabilitation facility in Sydney, Australia. This multidisciplinary team consists of HPs from rehabilitation medicine, nursing, physiotherapy, occupational therapy, psychology, social work and recreational therapy. Eligible participants had worked in the area of SCI for at least 12 months. A purposive sampling strategy was adopted to ensure a range of disciplinary backgrounds were represented.

Twelve HPs from the disciplines of occupational therapy (4), nursing (3), psychology (2), rehabilitation medicine (1), social work (1), and physiotherapy (1) participated. Eleven were female. Years working in the field of SCI ranged from 1 to 21 (years of experience: $M = 7.9$, $SD = 8.2$). From a list of possible religious backgrounds, eight HPs identified as 'Catholic', one as 'Anglican', and three as holding 'No religion'.

Procedures

Each disciplinary team leader at the SIU was provided with a letter of invitation to nominate representatives from their team. Interested HPs were then provided with further information and consent forms to sign. Prior to the commencement of each group, participants completed a number of demographic items.

Two focus groups were held. Each focus group consisted of a semi-structured interview of five questions aimed at exploring the topic of spirituality and its role within SCI rehabilitation (see Appendix 1). Focus groups were approximately one hour in duration and were audio-recorded and transcribed.

Data analysis

An inductive thematic analysis was used to identify codes and themes, utilising qualitative data analysis software (NVivo 10 for Windows) [29]. Initial codes were generated by the first author (KFJ), from which themes and patterns were identified. During the process of analysing data, regular feedback was provided by the other three authors (PD, LB, GKS), resulting in a group of themes which all four authors agreed upon.

Ethical approval

We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Results

Identified themes

Six themes were identified from the focus group data.

Theme 1: The meaning of spirituality for HPs

The first theme elicited from the data depicted the varying definitions and understandings of the term 'spirituality' for HPs themselves. The HPs conceptualised spirituality in

three key ways: (i) a sense of meaning or purpose; (ii) a belief in, or connection to, something or someone; and (iii) life values or 'goodness'.

Spirituality was closely associated with meaning and purpose, and especially so after SCI. Examples were provided of clients with spiritual or religious beliefs who believed their SCI had occurred for a reason. It was proposed that such clients construed the SCI as meaningful because it was part of 'God's plan'.

Second, spirituality was described as a belief in, or connection to, something or someone, whether it be God, the 'supernatural', something 'beyond this world', or just something bigger or greater than oneself. One HP described how she believed spirituality to be very closely related to religion: "Yes, I link it to God. For me it's a religious thing. But a deep, meaningful, almost a core feeling". For others, the meaning of spirituality was more diffuse, encompassing a connection to 'something', whatever that may be.

Last, spirituality was perceived to relate to how people lived out their beliefs, closely associated with life values or morals. This was particularly so in relation to care or compassion for others. One HP focused on the concept of 'goodness'. "I see it as 'spirit', as a good thing within your soul. And so that spirituality is how you bring that goodness out…I think it's that sense of wanting to look out for other people".

Theme 2: Spirituality as a help

A second theme emerging from the data was how spirituality was perceived to be a help during spinal rehabilitation. Spirituality was identified as a help by facilitating: (i) support from a spiritual community, (ii) hope, (iii) purpose, (iv) family connectedness, (v) an ability to cope, and, (vi) a way to 'move on'.

Spiritual communities were identified to help clients by providing both practical and emotional support. Examples were provided of priests visiting congregation members to give communion, or fellow believers arriving to conduct a Bible-study. Clients attending a religious ceremony with their spiritual community was seen to be a positive rehabilitation goal.

Spirituality was also perceived to facilitate hope. This included both hope for a miraculous cure and hope for other aspects of life. Spiritual beliefs were seen as one way that a 'sense of hope and positivity' could be provided 'through a really awful time'. There were also accounts of clients whose hope 'of a miracle' helped them in hospital and continued to help them in the community. Of these clients one HP said "they're still living the hope of a miracle, but they don't know what the miracle is". In this context, hope for a miracle was viewed as contributing towards a positive outlook, and something which may change over time. As raised later in Theme 3, at other times HPs expressed concern about clients who held more uncompromising hope for a 'miracle', believing it may hinder the client's rehabilitation.

Facilitating purpose or meaning in life was another way spirituality was identified to help SIU clients and their family members. This was deemed particularly true for those clients with religious convictions. It was thought that clients who believed this was 'part of the plan for them' were less frustrated and more accepting of challenges that they encountered. Trusting in God assisted clients by taking away: "that focus of me, me, me, me, me, me, me, why's this happened to me?" Instead such clients might say "okay it has happened to me, I'll work hard and God will then somehow show me how I can… continue living my life". One HP could recall times when clients told her how the SCI had changed the direction of their lives, given them a second chance, and been the best thing that had ever happened to them.

For the most part, discussion focused upon the coping and adjustment of the individual with SCI, rather than their family members. However, in one focus group, further reflection upon the family experience was provided by the social worker. This HP observed that those families with spiritual beliefs had a greater connectedness, a connectedness on "another level" almost "above the family".

There were several ways spirituality was identified to facilitate coping for clients and their families after SCI. A psychologist described how prayer or meditation could assist individuals in their process of adjustment: "even though they might describe not being religious at all they might still use that term [prayer] and just some of the cognitions or the self-talk that they're doing in their own mind … gives them comfort". Another HP reported how a client's religious faith had helped the client to cope, not only through the experience of his SCI, but his house burning down shortly after discharge. "But it was like what else can life throw at this man, and for him to retain his faith? You just go well there's a strength in there somewhere that's getting that man through life. He hasn't given up". The sub-themes of hope and purpose outlined above were closely associated with this ability to cope, which HPs perceived religious faith to facilitate.

Lastly, spirituality was observed as something which helped clients to accept their situation and move forward. Although some HPs clearly associated this attitude with spirituality, others were uncertain about what it was that helped clients to arrive at a place of acceptance and move forward. One client who was perceived to have coped well was described as an 'Aussie bloke' with a 'get on with life' attitude.

Theme 3: Spirituality as a hindrance

Another theme elicited from the data was that HPs perceived spirituality to sometimes be a hindrance. HPs perceived spirituality to be a hindrance; (i) when clients believed they would be miraculously healed by God, and (ii) when spiritual questioning resulted in anger or blame towards God, which subsequently affected other parts of an individual's life.

It was suggested that clients could disengage from rehabilitation processes because they believed God would heal them. "The control is outside of them, it's in a higher being, it's in God…they do sometimes seem to sit back a bit and think 'It's okay, I'm going to get better because God's going to heal me'". At least one HP found this frustrating, providing the example of how ordering equipment was difficult for an individual who did not think they would need it.

Another way spirituality was considered to be a hindrance, was when clients expressed anger towards God, or blamed God for their SCI. This blaming could become an "I hate everything" attitude. In some cases, this anger at God was perceived to have brought about division among family members, rather than connectedness.

Theme 4: How spirituality is indirectly addressed in practice

The majority of HPs reported that spirituality was not a topic proactively addressed with clients or their family members. Only the social worker and psychologists incorporated it regularly into their client assessments. Spirituality was, however, somewhat addressed in three indirect ways; (i) by facilitating clients to participate in religious activities, (ii) during relaxation/meditation groups, and (iii) during informal interactions with clients.

Facilitating clients to participate in religious activities with their spiritual community was one way that spirituality was perceived to be indirectly addressed. An example was provided of a Catholic nun whose spiritual community was 'like family' to her. Incorporating time for a church bible-study into a client's weekly timetable, and arranging physical access to a client's church, were other ways participation in religious activities was supported.

Another way spirituality was addressed was through a relaxation group run by psychologists. This group was described as incorporating some meditation, though it was not specifically referred to as spiritual meditation. "They're calling it relaxation but it's actually meditation, because most people go 'ooh, don't want to meditate'"

Spirituality was most likely to be discussed with clients and their family members during informal periods, when it was deemed to be less direct or confrontational. These periods occurred when the HP had more time, such as on a home visit, or when assisting a client with personal care tasks. One nurse commented: "If I'm … doing something that takes a long period of time with the client I will engage in just general social conversation … and then you will find that they will share information about their families and things like that as well…". One of the occupational therapists described how helpful the car journey on a home visit could be. "And you're sitting in the car with them driving for an hour and all sorts of conversations come up". Awareness of what was happening in a client's life could later direct what was discussed in therapy sessions.

Theme 5: Perceived barriers to incorporating spirituality into practice

The fifth theme arising from the data was barriers HPs perceived in incorporating spirituality in their practice. Three main barriers were identified; (i) the perception that spirituality was a private matter, (ii) professional boundaries, and (iii) staff discomfort when clients shared beliefs.

The first sub-theme identified was that HPs were reluctant to raise spirituality due to the perception that it was a private or personal matter for clients. One HP commented: "I personally try not to sort of pry on that level. If they want to bring it up they can bring it up but I don't really ask those sorts of questions". Others reflected how everything else about an individual's life is discussed with HPs, including sexuality, and bowel and bladder management. "Yeah, they can have [spirituality] to themselves, because now everything else to do with their body is tapped into and out in the open for the whole team to know about".

Second, associated with the notion of privacy was the idea that therapist-client boundaries hindered discussion of such topics. As one HP commented, "I don't talk about myself to clients…but that probably hinders how much they share with us". This contrasted with other HPs' accounts noted earlier, of more informal exchanges with clients during personal care or home visits.

Last, HPs mentioned that unwelcome sharing of beliefs from clients to staff increased their reluctance to discuss spirituality. One HP spoke of her discomfort when a client shared Bible verses with her. "I support her in whatever belief but feel awfully uncomfortable sometimes when it's kind of forced at you".

Theme 6: How spirituality could be better integrated into practice

The sixth theme focused on how spirituality could be better integrated into practice. Two key approaches were identified: (i) through facilitating access to physical space, and (ii) by reviewing rehabilitation processes.

The lack of physical space specifically dedicated to meet clients' spiritual needs was perceived to be a limitation. It was observed by HPs that clients of the SIU did not have access to a chapel or prayer room, nor access to the outdoors in the evenings. One HP commented: "I think the system probably doesn't allow them the freedom to tap into their spirituality …If lock down's 8 o'clock… but they want to look at the stars they can't do that". Another example was a client who couldn't "see any green from her room" when she arrived at the unit. Because this was such a significant source of spirituality for her, this need was addressed by moving her to another room.

Spirituality was considered to be a topic which was forgotten because "it's not embedded in our processes". The second way that HP suggested spirituality could be better incorporated at the SIU was through formal processes, such as multidisciplinary assessment meetings or client goal planning meetings. "It's maybe something we could incorporate at the beginning of our process…because I'm thinking there's other ways people express spirituality and some people meditate and some people pray and what have you, and if we knew that…". However, as outlined earlier, some HPs felt discussing spirituality at such meetings may encroach on clients' privacy. Others expressed concern the topic could be raised too early, before a relationship with the client had been established.

Discussion

This study demonstrated that although spirituality was recognised by HPs to be an important aspect of adjustment for clients and their family members after SCI, for most HPs it was not an aspect integrated into rehabilitation practices. Spirituality was most likely to arise indirectly, on an ad hoc basis and during informal interactions with clients. Perceived barriers preventing HPs from addressing spirituality included the perception that it was a private matter, professional boundaries and staff discomfort. One of the reasons for staff discomfort was the strong association held by staff between spirituality and religion, terms which were often used interchangeably during the focus groups. Two ways HPs suggested the role of spirituality could be enhanced were by facilitating access to physical space to address the spiritual needs of clients, and incorporating spirituality into rehabilitation processes, such as client assessments and goal planning.

The study's findings are similar to those within the broader area of health. Studies have found that although HPs agree upon the importance of addressing spiritual needs, lack of confidence can result in few incorporating it in practice [24–26, 28]. Barriers to addressing spirituality have included the perception that spirituality is a private matter [23, 24], lack of time [24, 27], spirituality being confused with religion [30], institutional barriers [30] and a lack of knowledge or skills in addressing the topic [24, 28]. Yet research also suggests that patients and other healthcare users would like to discuss spirituality, and feel that this is part of the HPs role [31].

There are several ways the issues arising from this study could be addressed. First, introducing staff training may be valuable. Better understanding of the concept of spirituality, and its relationship with religion, may assist staff to feel more comfortable raising the topic with clients. An example of such training is provided by Meredith et al [32], who conducted four workshops to improve the confidence and knowledge of palliative care staff regarding spirituality. Directly after the workshops they observed significant increases in staff levels of Spirituality, Spiritual Care, Personalised Care, and Confidence. Three months later improvements in Spiritual Care and Confidence were maintained. The success of such an intervention in the area of palliative care suggests that similar staff training could be beneficial in the area of SCI.

A second approach could be the introduction of a structured spiritual needs assessment. A plethora of such assessment tools and approaches are available for use within health [33, 34]. However, as McSherry and Ross [35] suggest, some caution is required. As some of the HPs in this study expressed reluctance to raise spiritual issues with clients, any systematic approach would require extensive collaboration with staff, and the implementation of appropriate training as outlined above.

The findings from this study can be used to inform broader based studies. Further research would provide additional information regarding the barriers and facilitators encountered by staff. This information would assist in the development of staff training programs, and the implementation of formal assessments or interventions.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Appendix

Focus Group Interview

Thank you for coming to this focus group today. The purpose of the group is to discuss how the role of spirituality is incorporated into the spinal rehabilitation process now, and

whether it could be enhanced. I would like to include spirituality for both clients and their family members in this discussion.

(1) How would you describe spirituality?
(2) One way spirituality has been defined is: "the sense of harmony and interconnectedness of the self, others, nature, and the ultimate Other" achieved "through a dynamic and integrative growth process that leads to the ultimate purpose and meaning of life" (Brillhart, 2005). Using this definition how have you seen spirituality make a difference among spinal clients and their families during rehabilitation?
(3) Do you think spirituality has a role in spinal rehabilitation?
    - If so, what do you think its role is?
(4) How is this role incorporated at present?
(5) What do you think are some ways that spirituality could be enhanced during inpatient rehabilitation?

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